

Children and Youth with Special Health Needs

Focus Group Summary

Author: Emma Connell and Rebecca Sales



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451 Lexington Parkway North | Saint Paul, Minnesota 55104
651-280-2700 | www.wilderresearch.org

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Key findings

Topic	Key points
Overarching themes	<ul style="list-style-type: none">✓ Parents discussed difficulty in getting access to benefits and services their child was eligible to receive. They perceived frontline staff as gatekeepers controlling if and when children could get services once parents asked, rather than navigators assisting them in accessing services.✓ Parents rely on other parents of children with special health needs to receive the information they believe should be coming from frontline staff.✓ A lack of assistance with care coordination was a major barrier to accessing appropriate care.✓ Parents benefit greatly from sharing information and supporting one another through in-person interactions.
Health care accessibility	<ul style="list-style-type: none">✓ Parents perceive frontline staff to be withholding information and/or access to services and benefits their child is eligible to receive.✓ High turnover rates among frontline staff limit organizational knowledge of available benefits and services.✓ Care coordination is difficult, and a lack of assistance with care coordination is a barrier to accessing health care and other services.
Health care affordability	<ul style="list-style-type: none">✓ Income limits for Medical Assistance eligibility force families to live in poverty.✓ Health care services not covered by insurance create heavy debt burdens for families.✓ Parents frequently learn of benefits they are eligible for from other parents of children with special health needs.
Flexible employment	<ul style="list-style-type: none">✓ Parents of children with special health needs will frequently change jobs and careers to be better able to balance caregiving responsibilities with employment.✓ Family and Medical Leave Act (FMLA) policy does not go far enough to protect parents of children with special health needs.✓ Workplace cultures vary widely and make a substantial impact on the feasibility of working and being a caregiver of a child with special health needs.
Child care	<ul style="list-style-type: none">✓ Appropriate child care options for children with special health needs are few and far between. They become more difficult to find as children grow older.✓ Child care professionals need additional training to provide care for children with special health needs; in particular, this is needed to support children with emotional and behavioral needs.

<i>Topic</i>	<i>Key points</i>
<i>Parent support and education</i>	<ul style="list-style-type: none"> ✓ Parents primarily receive information from other parents of children with special health needs; this information is often shared in Facebook groups. ✓ Parents identified a need for navigation services and for frontline staff to be better aware of and open to sharing information around available services and benefits. ✓ More in-person support groups would be beneficial for parents of children with special health needs.
<i>Well-being</i>	<ul style="list-style-type: none"> ✓ Parents of children with special health needs frequently tie their own well-being to the well-being of their child. ✓ Difficult experiences with health care professionals were a major source of stress for parents of children with special health needs. ✓ Opportunities for children with special health needs and their families to get together would support well-being.
<i>Cultural community: American Indian</i>	<ul style="list-style-type: none"> ✓ Parents reported positive, culturally competent experiences with school systems and some health care providers. ✓ A lack of resources in the community and dismissiveness from health care providers were barriers to receiving appropriate care.

Recommendations

Utilizing specific suggestions from participants, as well as themes that came out of this work, a number of recommendations are listed below. These recommendations address specific topics, MDH processes, and considerations for future work.

Topic related

- Create more, or improve access to, in-person groups for parents to share information and support with one another.
- Ensure parents understand all care options for their child, as well as the extent to which each option meets the child's needs.
- Provide guidance and support to parents and children around issues related to children transitioning to adolescence and adulthood, especially related to ownership of medical information, medical decisions, and child care options.
- Provide navigation services to families that proactively direct them to benefits and services their child is eligible to receive.
- Support the ongoing education and retention of county and state staff serving families with children and youth with special health needs.

Process related

- Strengthen existing, or establish new, relationships with organizations that serve parents from different cultural backgrounds to better share information with these families, as well as work with them to ensure their needs are met in a culturally appropriate manner.
- Utilizing the themes from this summary, MDH should consider adding follow-up questions to future surveys. This would give MDH an opportunity to gather specific information from a larger number of families who represent a greater diversity of experiences.
- Compile family feedback and insights from recent projects into one document to develop a more comprehensive view of things such as what types of parents have provided feedback, what topics they have addressed, and the suggestions. This could identify longer-term trends, as well as reveal questions or communities that may not have been considered.
- MDH should continue to enhance strategic partnerships with organizations that provide services to a large number of children with special health needs and their families. Because these families often interact with a variety of service providers and service systems, these partnerships will create more efficiency in identifying and addressing the needs of the children and their families.

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Introduction

The Minnesota Department of Health's Children and Youth with Special Health Needs Program works to improve the health of children with special health needs and their families by improving the systems that serve them, providing education and support to families and service providers, and shaping policy.

The Minnesota Department of Health (MDH) is required to complete a comprehensive statewide needs assessment every five years for the Title V Maternal and Child Health Block Grant. The goal of the assessment is to understand the needs of families in order to improve the health and well-being of children with special needs and their families and strengthen partnerships that support children and families.

During the summer of 2018, nearly 2,800 people responded to a MDH Discovery Survey to share their thoughts on the greatest unmet needs of women, children and families in their communities, along with what they need to thrive and live their best lives. Nearly 300 of those respondents identified as being caregivers or guardians of children and youth with special health needs. Following the Discovery Survey, MDH contracted with Wilder Research to conduct nine focus groups with parents of children and youth with special health needs to further explore the topics most often identified in the survey. The findings from the focus groups are summarized below.

Methods

Wilder Research worked with MDH to develop protocols to dig further into the most frequently mentioned areas of need for parents of children and youth with special health needs, as identified by Discovery Survey results. The six themes that were addressed in these focus groups were:

- Health care accessibility
- Health care affordability
- Flexible employment
- Child care
- Well-being
- Parent support and education

Each focus group focused on one topic area, with the acknowledgement that many of these topics are interwoven in a variety of ways. Each focus group lasted approximately 90 minutes, and each participant was given a \$50 Target or Walmart gift card to compensate them for their time. A total of 44 parents attended at least one of the focus groups.

In addition to topic area-specific focus groups, Wilder Research and MDH intended to conduct focus groups with parents of children with special health needs who belong to specific cultural groups. The study intended to conduct focus groups with Hmong, Somali, Spanish-speaking, and American Indian groups. Because of difficulty in recruitment, we were only able to conduct the focus group with American Indian parents of children with special health needs.

With input from Wilder Research, the Minnesota Department of Health conducted recruitment for the focus groups. Recruitment for the CYSHN focus groups utilized previously used MDH channels for advertising the focus group opportunities, including: distribution via MDH CYSHN staff contact lists, listservs, and professional networks, social media postings by parent/family advocates, and outreach and advertisement via Family Voices of Minnesota. Wilder Research was directly involved in recruiting for the American Indian family focus group. Registration surveys for the focus groups occurred via Redcap, and MDH CYSHN staff corresponded directly with interested parents to confirm their registration, inform them of their placement on a waiting list, and/or answer any specific questions about participation.

Limitations

Key themes should be interpreted with caution; this report cannot speak to the breadth of experiences parents of children with special health needs have due to the following.

- A number of parents participated in multiple focus groups. Because of this, we captured a depth of information from a smaller subset of parents.
- The channels used to recruit parents likely resulted in the parent participants being more well-connected and informed than parents who were not reached through recruitment efforts.
- Similarly, focus groups to be offered in non-English languages were not advertised in Spanish, Somali, and Hmong due to time constraints related to translation. This likely affected recruitment.

While focus groups questions gathered parent's experiences and perspectives for each topic area, types of questions asked varied across focus groups. For this reason, the information reported for each type of focus group varies.

This series of focus groups intended to have a series of culturally-specific focus groups to better understand the unique assets and challenges that come with belonging to different communities; because of the inability to conduct most of these, we have limited information about how different cultural communities uniquely experience being a parent of a child with special health needs.

Results



Health care accessibility

About the participants

- Six parents of children with special health needs participated in the health care accessibility focus group.
- About half of participants identified as white, and about half of participants identified as black or African American. No participants identified as Hispanic.
- Most participants' children had some form of public health insurance, which a couple of participants supplemented with private health insurance.
- Participants were asked to indicate which services their child receives; children most commonly received counseling/psychiatry or other mental health supports, Individualized Education Plans (IEPs), and in-home nursing care.

This focus group revolved around which services and providers are most difficult to access for parents of children with special health needs and what makes those services and providers difficult to access. Parents were also asked to discuss whether or not they have had to discontinue components of their child's medical care because of difficulty accessing it; what, if anything, has improved in terms of accessing health care services for their child, and what they would change about the health care system to improve access for children with special health needs. It should be noted that parents thought of the concept of "health care" broadly, and discussed a variety of care needs during this focus group.

All parents discussed experiences in which they have struggled to access health care and appropriate services for their child or children with special health needs. Parents commonly discussed the requirement that they act as advocates for their child; parents reported continuously researching what rights they and their children have and what benefits are available to them, as they frequently have to demand access to these services from different state agencies. Specifically, one parent spoke about work they had done to educate their school about how to create a 504 plan for their child.

I had to teach the school how to put a 504 together. They don't willingly give it to the parents at the beginning of the school year. They have it, but they don't give it to you.

All parents spoke about the lack of assistance from service agencies in determining what their child is eligible for and ensuring their child accesses benefits and services that they should be able to access. Parents discussed how high turnover rates for frontline

positions at state and county agencies are a barrier: they noted that new staff are less knowledgeable about what services and benefits are available for children with special health needs, which prevents them from serving as an effective navigator to the system.

Parents also discussed the fatigue that comes with coordinating medication, medical appointments, and paperwork for their children with special health needs. Parents of children with special health needs work with a variety of systems to access services and benefits for their child, but a lack of coordination between these systems pushes the role of care coordinator on the parent.

The fact is, most children who have complex medication needs also have complex medical appointments... It just adds another layer of complexity. You have systems that don't talk to each other. When you interact with someone new, you have to say the same things over and over again.

When asked what services or providers are most difficult to access, **parents discussed concern and frustration that insurance providers can determine which services and treatments children are able to access.** One parent discussed their concerns with step therapy, in which insurance requires that lower-cost medication and care must be tried and deemed inadequate in order to access medication and care that is more expensive. Some parents with younger children also discussed fears of their children aging out of being eligible for services as they grow older.

Parents discussed situations in which they have discontinued care because of a lack of respectful and competent care. Focus group participants provided examples of when they had experienced race or gender bias in the health care system.

From my own experience, when you are dealing with a "black" disease, there is a bias. When our children are babies, in this case, a brown baby, the moment they look like a black adult, the bias kicks in and now the way they treat you is different. [We were] seeing a physician who minimizes women... they treat you like "Oh, you poor thing!"

Parents were asked to provide specific suggestions for how to change the health care system and improve access; their suggestions included:

- Improve consistency in services, benefits, and paperwork requirements across counties.
- Provide navigation services for families to actively suggest what benefits and services their child could receive.
- Break down silos between different systems; parents most frequently mentioned silos between the school system and health care providers.
- Critically assess the age at which children with special health needs can withhold their medical information from their parents; some parents noted that their children can limit

what information they receive once they reach age 13, which can limit the extent to which they can care for their child. This was particularly concerning for parents of children with an emotional or behavioral issue, as they were more concerned their child would cut off their parents' access to information.

- Allow for alternative medicine to be covered by insurance; some parents mentioned that alternative or holistic treatments appeared to help their child.



Health care affordability

About the participants

- Five parents of children with special health needs participated in the health care affordability focus group.
- Participants predominately identified as white, non-Hispanic.
- Three of the five had both public and private health insurance for their child with special health needs, one exclusively had public health insurance, and one exclusively had private health insurance.
- Participants were asked to indicate which services their child receives; children most commonly received counseling/psychiatry or other mental health supports; speech, auditory, or vision therapy; and respite care.

Within this focus group, parents of children with special health needs were asked whether or not their child's health care was affordable for their family and what the concept of affordability meant to them. They were also asked to discuss what services are most difficult to afford and what trade-offs their family has made to afford necessary health care. Lastly, parents were asked to discuss what services or information they had used to better understand the cost of their child's care or to better be able to afford it. It is important to note that "affordability" of health care looks different for families of children with special health needs, as their needs are oftentimes essential and inflexible; families will frequently make sacrifices in all other areas of their lives to be able to pay for essential health care for their child. It should be noted that parents thought of the concept of "health care" broadly, and discussed a variety of care needs during this focus group.

Parents face severe financial hardship both from high health care costs and from income limits attached to benefits.

All focus group respondents discussed the financial hardship that has come with their child's or children's medical condition, either because of the cost of health care when they have only been able to receive appropriate services and benefits through out-of-

pocket expenditures, or because of the income restrictions of Medical Assistance. For many families of children with severe health needs, Medical Assistance is the only way in which they can afford the level of care their children need. Focus group participants spoke about how they have had to choose to limit their own income, to the detriment of their overall standard of living, in order to access Medical Assistance. Respondents discussed how, without Medical Assistance, they would be completely consumed by medical debt.

In order to access some of these services, you have to choose to be oppressively poor.

The reason I am poor is because I have to take care of my son... It is not affordable. It is only affordable because we are poor.

Focus group respondents spoke about the financial hardship they face when they are not eligible for Medical Assistance. One respondent discussed the difficulties faced when her child's medical condition was so rare that many components of care were not covered by insurance. Out-of-pocket expenses were extremely high for this respondent, causing her to lose her home and require her to work four jobs. Still, this respondent reported being consumed by medical debt.

Respondents struggled with the concept of "affordability." Focus group participants often stated that medical care for their child was affordable because they ultimately are able to pay for them. However, they added the caveat that by paying for their child's medical needs, they sacrifice in other areas of life.

I can say "yes" based on how we tailor our budget. In budgeting for that, we miss other things that add to the quality of life. We have to make it affordable because we have no choice.

A lack of knowledge about the cost of health care services was a barrier highlighted by parents participating in the focus groups. Not fully knowing the total cost that will be billed was a major stressor for participants.

Nobody presents you a tailored menu of what the options are. Is it affordable, is it enough?

Other parents of children with special health needs are a vital resource.

Focus group participants were asked what services or information they have used to make their child's health care more affordable or to better understand the cost of their child's care. Parents frequently relied on other parents to learn about benefits their family might be eligible for. They also discussed the variability of helpfulness in case managers; while some have been incredibly helpful in identifying opportunities for families, others have lacked necessary knowledge about available services and benefits.

Administrative requirements impose added costs and barriers to care.

Parents took the opportunity to discuss services that have been unhelpful to them. Paperwork requirements are a burden for families, and parents spoke about the costs to the state and counties that are incurred because of the amount of paperwork involved in receiving benefits. For example, one mother discussed having to annually prove to the county that her daughter is deaf. She discussed the burden on her family, the health care system, and the county as each year they are required to visit an audiologist and submit a packet of paperwork confirming this life-long condition.

I would submit that there is really a greater monetary problem and extra cost to re-proving everything. If they stopped treating everyone as a liar until proven not, that might free up a lot more funds.



Flexible employment

About the participants

- Thirteen parents of children with special health needs participated in the flexible employment focus group.
- About half of participants identified as black or African American, and the other half predominately identified as white.
- Nearly all parents reported that their child had public health insurance; a couple of participants supplemented this with private insurance, and a couple of participants exclusively had private health insurance for their children.
- Parents were asked to identify which services their child received; most commonly, parents reported their child receiving counseling/psychiatry or other mental health supports, Individualized Education Plans (IEPs), and adaptive sports and recreation.

This focus group focused on balancing employment and being a parent of a child with special health needs, including how, if at all, parents have adjusted their work life to be better able to care for their child. They were also asked what policy or workplace culture shifts would better support them as parents of children with special health needs. Lastly, parents were asked to share examples of when they had effectively worked with their employer to be able to balance work and caregiving.

Overall, parents discussed how current workplace policies and practices prevent them from being able to control the kind and amount of work they participate in.

Many parents have had to leave the workplace, and current policies and practices more consistently force mothers to leave the workforce than fathers. This can prevent women

from being able to pursue careers and prevents fathers from being the caregivers they would like to be.

I was always passed up for promotions because I have a special needs child. I would never apply for promotions or special assignments because I knew I had to miss work and leave work at any time [to care for my child].

Parents were asked how they balance employment and caregiving efforts. Respondents discussed:

- **Altering work arrangements**, including changing careers to have a more flexible schedule and trying to work more typical daytime work hours to be home at night.
- **Relying on others**, including hiring in-home support and finding an ally within the workplace to advocate for them.

While focus group participants discussed certain strategies to better manage the competing responsibilities of being in the workforce and a caregiver, all agreed that they had not been able to achieve a balance and that their responsibilities as a caregiver usurp their ability to freely choose when and how they participate in the labor force.

Children aging had different impacts on parents, depending on their specific medical needs. For one parent, their child growing older presented more flexibility to return to work, as the child was more independent. However, another parent struggled more as their child aged, as child care was more difficult to find for an older child.

It all depends on my child's age. As he got older, he wanted – or needed – me less, so that helped me be more flexible. I wanted to be a presence in his life before he got older.

Parents spoke about intentionally choosing or changing jobs and careers to have more flexibility to serve as a caregiver or more understanding supervisors and peers.

Respondents discussed difficulties working in managerial positions or in the for-profit sector, which limited flexibility for parents to respond to immediate needs and scheduled appointments for their child. This led several parents to pass up or not pursue promotions.

I work at a job [that does not directly interact with clients] so that I could have more flexibility. I get scared [to leave my child with others] because other people who don't know how to treat my daughter can get hurt or injure my daughter.

Focus group participants discussed the exhaustion that comes from being a parent of a child with special health needs interfering with their ability to work effectively.

By having what effectively amounts to two jobs – one professional and one as a caregiver – these parents are not able to take time to sleep as much as they need, much less take sufficient time to recover mentally and emotionally from the work day. They discussed that this exhaustion prevents them from being able to work at the level they otherwise would be able to.

We caregivers get fatigued and that causes stress and depression, which isn't healthy for an employee anywhere.

Focus group participants were asked to discuss their experiences with workplace policies that have helped them, or what changes to policy would better serve them as parents of children with special health needs.

Respondents described shortcomings of existing laws that were built to protect caregivers. Respondents discussed Family and Medical Leave Act (FMLA) policies:

- This law protects employers from firing caregivers for taking leave, but does not protect them from retaliatory behaviors of employers. Respondents described work they had done to educate themselves about and defend their rights within the workplace; employers and even individual supervisors will interpret the policy differently and will frequently do so with an approach that is favorable to the employer rather than the employee.

You get to be protected legally at your job, but you're not protected from the behavior of your peers. They will use anything to push you out of your job and make your life miserable.

- Different workplaces will provide different levels of pay to men and women taking leave. While FMLA allows caregivers to take time off without being fired, it does not stipulate whether or not an employer needs to pay the caregiver a percentage of their wages while they are out. This flexibility allows employers to compensate men and women differently for caregiving work, which aligns itself with historical assumptions about whose work it is to be a caregiver. Men will frequently be provided less flexibility and pay for caregiving work.
- New employees do not benefit from FMLA. Respondents discussed how employees in their first year of work are not eligible to take leave through FMLA, though their children's health needs will not wait during this interim phase.

They should reduce the one year limit to be on the job before FMLA kicks in, because our kids' health condition won't wait a year.

- FMLA reflects typical understandings of family structure, which are frequently blurred for families of a child with special health needs. For example, older children will frequently assist with caregiving responsibilities for their siblings with special health needs; however, these caregivers are not necessarily protected under FMLA policy.

As a single mother, I think they should recognize my oldest daughter, who also helps out as a caregiver. They should have a second household member who can get FMLA protection as well.

Increased flexibility within workplace cultures would better allow parents of children with special health needs to work effectively.

- Different workplace cultures influence how peers react to an employee's needs as a caregiver. Respondents discussed how colleagues and peers will look down upon them for taking leave or having a flexible schedule.
- Respondents noted that the ability to telework can be critical in allowing them to work. They suggested that workplace culture should shift to a focus of the quality and amount of work completed, rather than the amount of time physically spent within an office. Within this, respondents discussed how working in a geographic area that has fast and reliable internet access can change the opportunities for parents of children with special health needs; parents in rural areas are less likely to have the infrastructure needed to be able to work remotely.

■ *It's not about the physical aspect of being there, but instead, the work we're producing.* ■

- Respondents discussed how employers will act punitively toward parents who make “too much” use of employer provided benefits, such as workplace counseling.
- Parents of children with special health needs are oftentimes unable to discuss the difficulties of what they are experiencing or show emotions within the workplace. Respondents discussed how fathers are particularly unable to feel comfortable expressing emotion about their caregiving responsibilities or household situation because of societal norms.

■ *It's harder for a man to show emotions or break down. I had to learn how to share and talk about my feelings. Especially as a black man, I have to portray a certain image that's expected of me.* ■

- Employers that allow their employees to donate paid time off (PTO) between themselves can benefit parents of children with special health needs; focus group respondents discussed how they would frequently run out of PTO, and that donations from colleagues allowed them to take time off to better take care for their child or themselves.

■ *Donate time to your coworkers. I'm not Super Woman; I need breaks, too!* ■



Child care

About the participants

- Five parents of children with special health needs participated in the child care focus group. Participants predominately identified as white, non-Hispanic.
- Three of the five had public health insurance for their child, one of whom supplemented that insurance with private insurance; three parents had private health insurance for their child with special health needs.

- Parents were asked to identify which services their child received; most commonly, parents reported their child receiving Individualized Education Plans (IEPs), occupational therapy, and counseling/psychiatry or other mental health supports.
- Parents were also asked to list any financial assistance they are receiving for child care for their child with special health needs; three parents reported receiving consumer-directed community supports (CDCS), and one parent each reported that they received financial assistance for child care through their Developmental Disabilities (DD) waiver and through Medical Assistance.

Parents were asked to discuss their current child care arrangement, including what they like about their current child care and who provides care for their child when their usual caregivers are unavailable. Parents were also asked to discuss what challenges they have experienced in accessing appropriate care for their child, what they would change about their current child care arrangement, and how, if at all, their current child care arrangement makes it difficult to balance caregiving with work.

Appropriate child care options are few and far between.

All respondents discussed the difficulty in finding and maintaining any child care options that are adequate for their child. Providers that are capable of working with children with special health needs are rare, which can be especially difficult in rural areas of Minnesota. Once children have been enrolled in child care, they can be expelled because of behavioral issues, be unable to continue because of an inability to potty train, or otherwise age out of care.

Focus group participants were asked who provides care for their child with special health needs, both who provides care regularly as well as who provides care when the regular provider is not available. Respondents mentioned utilizing the following providers:

- **Child care providers:** Respondents noted that child care providers are used as regular care providers. According to parents, this would ideally be an inclusive child care provider, meaning they have appropriate staff, expertise, and funding to care for children with special health needs.
- **PCAs via a consumer-directed grants:** Respondents have used grants and state benefits to coordinate one-to-one care for their child with special health needs, oftentimes by hiring a personal care assistant (PCA). Respondents most often discussed using PCAs as their regular care providers, more often than an option to fill-in when their regular care is not available.
- **Family and personal networks:** Respondents frequently noted having family members, neighbors, or others they know personally step in for respite care when needed, but mentioned that this can be difficult and inconsistent.

Changes in provider training and requirements of children would reduce barriers to accessing appropriate child care for children with special health needs.

- *Knowledgeable staff.* Parents discussed a general lack of disability and medical condition-related knowledge among child care professionals. This can prevent children with special healthy needs from having appropriate, high-quality care, or even from being able to receive care at all.

What I found is that the teachers and staff did not have the education needed to deal with a preschooler with this behavioral issue, and I expected that. They asked her to leave... What I ran into is a lack of knowledge of otherwise well-intended, good people.

- *Requirements that children be potty trained.* Children with physical, mental, or emotional/behavioral health needs may not reasonably be potty trained by age 3, a common age at which child care providers require that youth be potty trained to continue receiving care.
- *Provider responses to emotional and behavioral needs, as opposed to physical needs.* Focus group participants noted that while many child care centers and providers are open to working with children who have medical issues that are physical in nature, they are resistant to providing care to youth with emotional or behavioral problems. This has resulted in expulsion of children from child care settings.
- *Children growing older.* As children with special health needs age, their needs change. Many child care organizations and providers are unable to cope with these needs. Specific issues parents discussed included:
 - A shortage of PCAs who are strong enough to carry an older child, especially children and older children with heavy medical equipment like wheelchairs.
 - Unmet infrastructure needs for older children who are not potty trained.
 - A lack appropriate care options for teenagers with special health needs who menstruate.

We need two adults to lift her up and change her. She uses a wheelchair, and they need a table to change her. My PCA brought her swimming, which was fine because they had recently remodeled, but there was no table for her to change. There's always a roadblock.

Organizations specifically targeting children with special health needs are helpful but rare.

Parents highlighted the Center for Inclusive Child Care and Fraser as organizations that provided tailored and especially good care for their children. Some parents were connected with appropriate child care through Gillette Children's Specialty Healthcare and appreciated their assistance with navigation.

Parents praised how knowledgeable staff were at these organizations and discussed the relief they felt in knowing their children were being taken care of well. Staff at these organizations were also able to connect parents to helpful resources or information for them to use at home and when their child was not in the child care setting.

Focus group participants discussed suggested improvements to their current child care arrangement. They included:

- Increase training requirements for child care providers, supported by funding.
Unless the experience is required and funded, it won't happen.
- Change Minnesota state policy to forbid child care providers from requiring that children with special health needs be potty trained by age 3 to receive care from in-home or center-based care.
- Designate supports for licensed child care providers to call when they need information or guidance on a particular issue they experience with a child.
- Increase child care availability in summer.

Parent support and education

About the participants

- Four parents of children with special health needs participated in the parent support and education focus group.
- Participants identified as black or African American, white, and bi-racial. All participants' children had public health insurance.
- Parents were asked to identify which services their child received; most commonly, parents reported their child receiving counseling/psychiatry or other mental health supports, physical therapy, adaptive sports/recreation, assistive technology, and occupational therapy.

Within this focus group, parents were asked to discuss which resources were most and least helpful for them when they had a question related to their child's health condition. They were also asked to discuss how they get connected with other parents of children with special health needs and what services and supports they would like to receive more of.

Parents most frequently reported that other parents of children with special health needs were most informative. Many parents discussed searching Google for answers to specific questions about their child and their needs, especially when they do not know of other sources of information to go to.

When my son was born, there was no Google and internet... As we fast forward ahead, I usually use Google and Facebook groups to get people's opinions.

Respondents also mentioned using the following resources for information when they have a question related to being a parent of a child with special health needs:

- Facebook groups intended for parents and family members of children with a particular health need
- Family Voices of Minnesota
- Professionals working with their child, including occupational therapists and case managers

Parents discussed sources of information that have not been as helpful to them. Some parents discussed the high turnover rate in organizations that provide services; because of this high turnover rate, staff are frequently unaware of different services and information they could offer to parents. Parents discussed having to take over the role of information seeking and sharing with other parents themselves.

I do a lot of it myself. I feel like, what's the point of having a case manager if we constantly have staff changes? I have to be on my own and do it myself.

Focus group participants were sympathetic that working in this field is difficult and that burnout is real. However, they have experienced staff who are unwilling to learn new things, especially from parents of children with special health needs.

Focus group participants were asked what supports they are not getting enough of that they would like to receive. They included:

- In-person parent support groups
- Inclusivity in programs and services targeted at children, especially for children with emotional and behavioral needs
- Opportunities for children with special health needs to meet and connect with other children with similar needs

My son always gets excited when he finds other kids like him. More can be done so that we can bring other kids together – we can reinforce that they are not alone, and there are other kids around, too.

- Support accessing community resources and being involved in the community. Additional support could help address issues participants discussed including parents wanting to visit or speak at city council meetings, but being unable to because of their child's emotional or behavioral needs or being; being unable to access the internet at the local library because of the child's behavioral issues and the lack of internet at home.
- Assistance in understanding what different benefits and supports are available to parents of children with special health needs. Examples of this include navigator services or conferences with information on available resources and sessions with information relevant to parents of children with special health needs.



Well-being

About the participants

- Nine parents participated in the well-being focus group.
- Over half of respondents identified as black or African American, with the remaining respondents identifying primarily as white.
- All respondents indicated that their child has public health insurance, though two parents indicated that this was supplemented with private insurance.
- Parents were asked to identify which services their child received; most commonly, parents reported their child received counseling/psychiatry or other mental health supports, Individualized Education Plans (IEPs), and adaptive sports and recreation.

Within this focus group, parents were asked to discuss what coping well as a parent of a child with special health needs meant for them, who they look to for support, and what they do to take care of themselves. Parents were also asked to reflect on what aspects of being a parent of a child with special health needs was most stressful for them.

Parents seek a “new normal” for themselves and their families, and feel things are going best when they see their children make progress and receive support from others.

Parents were asked to describe a time when they felt they were coping well with parenting and overall feeling good. Many parents said they have never felt fully calm, and that it is helpful to distinguish between coping and feeling that things are going smoothly; they spoke about how coping oftentimes means finding a “new normal,” where not everything is perfect, but it aligns with a new set of expectations for how life will look for their family. Parents often tied their own well-being to the well-being of their child with special health needs, noting that they felt better about themselves and their parenting when their child was progressing or coping with their condition.

I don't think coping well always means things are going perfectly...I never realized that I was coping well until I was in a place where I wasn't coping well.

Parents discussed sources of support that helped them feel they were coping with their responsibilities as a parent of a child with special health needs. This was frequently other parents of children with special health needs, who not only serve as a resource, but also reassure parents that they are not alone. Respondents were most able to connect with other parents through Facebook groups; in-person connections are less frequent. Parents spoke about the lack of in-person support groups for parents of children with special health needs, especially in communities farther outside of the urban center of the Twin Cities.

Respondents also commonly mentioned connections to family, friends, and religious communities as being sources of support and reassurance. Some parents mentioned services like respite care and having a caseworker as being essential to feeling good and in control of their lives.

Parents also mentioned specific strategies they use to take care of themselves. Many parents spoke about the importance of seeing a therapist. Others spoke about taking time for self-care by finding some time in the day to meditate or listen to music. Oftentimes, parents had to make time in their day for self-care by sacrificing sleep, as many work in addition to their responsibilities as a caregiver. Parents also discussed the importance of getting outside or going to a calming place like a library or their place of worship to decompress.

Difficult experiences with medical professionals are a primary stressor.

Focus group participants were asked to discuss what they consider to be the most stressful part of being a parent of a child with special health needs. Parents discussed a lack of empathy from doctors, a lack of frontline workers who can connect individuals with services, and having to interact with the general community as primary stressors. A couple of families were affected by sickle cell anemia; the condition is largely contained within the African American community, and families reported that the intersection of race and illness resulted in unpleasant and stressful experiences with doctors. Parents who did not face the same cultural barriers to quality care also noted experiences with poor bedside manner from medical professionals, which has kept families from having consistent health care providers.

When you're in the hospital, there's a lack of education and empathy from staff and doctors. They're so quick to judge. [A doctor] asked, "Who did you get this from?" ... [There is] so much judgement and lack of education because it's not in your community and you don't care about it.

When our regular pediatrician retired, we had to find another one. We have not found one yet.

Another common stressor that parents spoke about was the necessity of holding all information that is relevant to their child. Across all focus groups, parents expressed frustration with having to know what services are available to them and the rights of their children; parents discussed having to be aggressive advocates for their children to receive services rather than having front line staff at schools, counties, and statewide departments understand what services are available and inform the parents of their options.

Parents most frequently receive information from other parents of children with special health needs.

Focus group participants shared what resources had been particularly helpful to them. More than anything, parents discussed the importance of gathering information from as

many places as possible and viewing all networks as potential resources. Some specific organizations parents shared as helpful were:

- Condition-specific networks of parents and their children
- Condition-specific Facebook groups
- The Make–A–Wish Foundation
- Safe Families
- Hope Kids
- PACER

Parents requested more in-person support groups.

Parents commonly discussed a need for more support groups for parents of children with special needs; parents reported getting most of their support and connections from parents of children with the same or similar health conditions through Facebook groups. In-person meetings or gatherings with families were commonly discussed as a need for the community. Some parents noted that if resources were available to them, they would be interested in starting parent support groups in their area.

Focus group participants also commonly discussed difficulties in their children being outside of the “sweet spot” in which most benefits are targeted. This includes having fewer services available to older children and having children who are “not disabled enough.”



Cultural community: American Indian

About the participants

- Seven parents of children with special health needs participated in the American Indian focus group.
- Most participants’ children had public health insurance, with one parent supplementing that insurance with private health insurance and one child exclusively being covered by private health insurance.
- Parents were asked to identify which services their child received; most commonly, parents reported their child received Individualized Education Plans (IEPs) and speech, auditory, or vision therapy.

Within this focus group, participants were asked to reflect on and describe positive experiences they have had in receiving competent care for their child, what assets being a part of the American Indian community brings, and what challenges they face because they belong to the American Indian community.

Parents felt supported by their families and community.

Focus group participants were asked to reflect on the ways in which being a part of the American Indian community makes it easier and more difficult to be a parent of a child with special health needs. Parents discussed community understanding and emotional support as helpful, and in particular, appreciated when they could speak with other parents of children with special health needs in the American Indian community.

I think I feel more comfortable knowing somebody in the American Indian community also has a similar experience as me, so we can help and support each other.

Within the community, everyone is more understanding about our problems and needs. They help each other when something is going on.

Parents describe the American Indian community as under-resourced, creating barriers to accessing appropriate care.

When reflecting on the ways in which being a parent of a child with special health needs is more difficult as a member of the American Indian community, focus group participants discussed their community and those belonging to it being under-resourced.

Most commonly, parents discussed being torn between sending their children with special health needs to a public school, as opposed to a tribal school. While these parents preferred to send their children to tribal school as a way to connect them with their heritage, they discussed how public schools are able to provide more services for their child.

When I was pregnant, I thought that my child would go to tribal school. But now he is the only Native kid in the public school... It is just because of the type of services at the schools that he has to go to public school.

Parents also discussed challenges they experienced with health care providers, making it difficult to have complete knowledge of their child's health condition and needs. Specifically, parents discussed difficulty in getting appointments, having doctors take the time to learn about the child's symptoms, and in hearing back about test results.

When [my child] did his welfare check-up, [the doctor] checked us for like, 10 minutes because she was 20 minutes late from a previous meeting. We didn't get into any details in the appointment. My sister told me to go to her niece's doctor... that doctor was the first person to find out [our previous doctor didn't] even talk to us, or ask us to find out [my child's symptoms and experiences]. But when I went to my niece's doctor that took time with you, it is like night and day.

However, one parent discussed a positive experience in receiving care through a particular Twin Cities metro clinic. Staff at the clinic were understanding of the family's preference to stay away from medication when possible and altered the treatment plan to reflect these preferences.

Nowadays, kids are just put on pills. I just want an alternative to pills. At the clinic I feel they have a bit more understanding of Native culture. I feel more comfortable with them. I feel like other hospitals should have cultural sensitivity trainings.

Parents also discussed issues they had in finding the money to pay for additional services their child needs, like tutoring, and judgement they face from others. For example, one parent of a child with behavioral needs discussed being looked down upon in public settings.

If I'm in the middle of Target, the white people will look at you and shame you.

Parents most frequently had positive experiences with school-based professionals.

Focus group participants were asked to reflect on a time in which they felt they received good health care or support services, and what made that experience positive for them. Parents discussed positive experiences in which they were given support, either emotional or informational. Most commonly, parents discussed having positive experiences with social workers and other staff at their child's school.

My kid is special needs and he needed help. Nobody helped me, but the school stepped in and helped me.

I thought I would never hear anyone praise [my son] and say he can accomplish it. I praise the school for having their supportive services. I was very happy... getting positive feedback that your child is doing well and improving.

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451 Lexington Parkway North
Saint Paul, Minnesota 55104
651-280-2700 | www.wilderresearch.org

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